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ABSTRACT

A psychologist, who is the father of a child with a neuromuscular disorder, discusses psychosocial services for special needs children and their families. Parents are identified as the key to the family's mental health. Parents' feelings upon learning of their child's handicap include anger, blaming others and self, and guilt. These feelings are followed by grief, depression, and physical and emotional exhaustion, often aggravated by financial problems and changes in relationships with friends. The handicap impacts on siblings as well, as family attention is focused on the handicapped child, and nonhandicapped siblings are expected to assume more home responsibilities. As the handicapped child becomes aware of the handicap, feelings of loss, grief, anger, hopelessness, and despair may occur. A team of professionals trained in mental health skills is proposed to meet these psychosocial needs. The team should consist of a coordinator, social worker, physical therapist, nurse, religious leader, and medical staff. The team's initial role in helping the family would be crisis management; its role would change over the years as family situations changed. Other roles might include psychotherapy, educational planning, and information provision. Support groups are also an important component of providing psychosocial services. (JDD)

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PSYCHOSOCIAL SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

I have been asked to talk about psychosocial services needed by children with special health care needs and their families. We must remember that the basis of a constructive life rests in the development of the individual's mental health. You can teach someone to walk, etc., but their life may remain an empty shell if their mental health is impaired. To determine what mental health services must be considered, we need to address experiences which seem to be common to most people involved, and we must be flexible enough to relate to individual situations. To ask people what they feel they need, we should develop a broad questionnaire, which could be mailed and hand-carried to samples of the target population, on a nation-wide basis--then, each community should conduct a self-assessment to determine what services they have, and what they need to develop.

In the absence of such a questionnaire, I'm going to try to give you an overview of some of the experiences of our special health care children and their families, and then relate to possible psychosocial services to be provided.

I'll start by discussing experiences which I think are common to parents, and then, I'll include the siblings and finally, the special problem children. The parents are the key, of course, to the mental health of the family. They have to be O.K. <u>first</u>. I think the experiences I list are common, regardless of when a child and family enter the "system"--whether by birth, sickness, or accident. To illustrate, I will tell part of my story, along with some other people's stories which I have observed along the way.

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I now have three children--we entered the "system" when our youngest child, Brigette, was born. She is now four and one-half years old, and presents a neuromuscular disorder, called arthrogryposis at the present, for lack of a better diagnosis. Very briefly--Brigette's birth was a rather shocking experience. She was carefully lifted out through a caesarian section--her legs were twisted, her body was very thin with no muscle tone, and she couldn't move. My wife overheard the doctor say, "It looks like a spinal injury", but the doctor didn't tell us this. Earlier, at the insistence of our doctor, we had had an amneosyntesis; and my wife had held a small child at three months into her pregnancy, who then began to vomit, etc.--he evidently had the flu, or something. Perhaps out of the need to quickly understand what has happened, and to do something to relate to our dismay and helplessness, or to "fix it", we start blaming--if only.... It's the doctor's fault, my wife thinks it's her fault, I wonder if it's my fault--afterall, I had thought that the amneo was safe.... And the blaming doesn't stop--it just changes. Guilt follows us in our self-blame too--and anger is always available to us. So, we have anger, blaming others and self, and guilt.

A second general psychological experience was a strong sense of loss. The loss is incredible. Our daughter couldn't move. A physician told us that if she were to live, she may be a quadraplegic. (That night, she stopped breathing, but was revived). The loss is immediate--and again, it doesn't end. There is the loss of a beautiful birthing experience, the joy of birth, of new life, the parent-child interactions, the great beginning. Instead, after all the years of anticipation of parenthood, the experience is altered, abruptly, and in a very cruel way.

Connected with loss is the often reported strong sense of being cheated--it just isn't fair. The parents won't see their boy grow up in their image, they won't watch his little league baseball games or teach him how to play basketball; or, their daughter won't be in dance, gymnastics, or water ballet (as my oldest daughter was). Again, from an early age we dream our dreams--for most of us, our children are to be the most important part of our lives--and for many parents of such children, this dream is shattered.

Grief usually follows--in time, it can become all-pervasive--and although we learn to cope, the potential for grief doesn't ever end. When a loved one dies, we think we have died as well, but perhaps after a few years, we've reached some sort of closure or direction, and are moving ahead with our lives. But with a handicapped child, we grieve, and just when we think we'll be O.K., something new happens, and we're opened up to grief again. For example, you're child doesn't sit up, and still can't sit up--then perhaps one day she does--and you're ecstatic--until you see other kids her age running, with their hair blowing in the wind; or, on the first day of kindergarten, a milestone, other kids are running to school, but your little girl goes in on crutches, in a wheelchair, or is carried into a special classroom. So, grief can subside, only to re-emerge over many years ahead every time your child fails to experience the mastery milestones of life. And remember, that early grief can harm the ability of the parent to bond with the child, and that can do great psychological damage to the child.

Like everybody else, people who are currently grieving must still make decisions during the normal course of days, weeks--

perhaps out of the need to rectify our special grieving situation, to gain closure, a sense of control, we may be vulnerable to make some very poor decisions--e.g., "I need to get drunk"; "I need to have an affair"; "life is worthless"; "there can't be a God, so life is hopeless, just a joke"; "I may as well be dead"; or, we better quickly sell the house as we can't afford it anymore"; or "we may as well sell our recreational equipment, because we can't ever use it again", etc..

Grief can lead to psychological factors of depression and despair--with the usual clinical signs of depression--mid-morning awakening, feeling poorly in the A.M. hours, withdrawal, apathy, loss of weight or weight gain, etc., often with suicidal thoughts.

For many parents with a severely handicapped child, physical and emotional exhaustion can follow after a while--along with being over-whelmed with the complexities and constant demands of the task at hand. Couples can stop nurturing each other--all energy goes to work, maintenance activities, the handicapped child, and if other children are in the family, their needs continue--and husband and wife don't nurture each other any more.

Financial problems are almost always quite real. Consider that most families are struggling to pay bills, to buy a home, to save for a child's college, etc.--add to this the on-going medical bills and other expenses of a special health care child--and we see families stressed. Often mothers will elect to stay home to take care of the child, and her income is eliminated. The father now has to earn more money than ever. He will work longer hours, take more risks, and be under much grerater stress--and it doesn't stop. He will be home less, will have less patience, and will need more emotional supporet from his wife. But he won't ask for it.

She will need the same, as she is home longer, alone, and works continuously. She will be too fatigued to give to her husband--and he won't have much to give to her. And this, now, is your life. Even the most mature parents can ignore the other's needs, can hurt the other's feelings and feel hurt too, and the marriage can slowly disintegrate. As in cases of the death of a child, many couples divorce. Now imagine a single mother trying to care for a severely handicapped child alone....

Once again, imagine you have just experienced the birth of a special health care needs child into your family. Initially, friends come to see you, your family may visit to support you--but in time, they go away, and you're left to deal with it alone. You may not feel comfortable obtaining a baby sitter--nobody loves kids as much as the parents, and a baby sitter may not be careful enough with your "at risk" child. So going out is quite a project. Friends have a dinner party, and say, "No kids please", and you don't go. The same goes for a movie, a ballgame, getting your hair trimmed, and buying groceries is a major ordeal. The neighbors wonder why your lawn isn't mowed, and your leaves aren't raked. Basically, you can't get out of the house. My wife has recently said this has been one of the most difficult aspects of her situation--the inability to have a break, to talk with other adults, or to accomplish little tasks, such as cleaning the house.

Over time, even good friends may pull away--the nature of your relationships has changed. You look forward to the visiting nurse, or, if you're lucky, a physical therapist will come to your home during the summer months--they become your "friends". Your weekly schedule consists of mandatory doctors appointments, along with long hours of waiting in their reception rooms, usually several trips per week to a physical therapist (no time for you

to go to the dentist). And in many cases, as in our case, you start looking for "the expert" who will be able to tell you more--and this often leads to disillusionment, and a throwback into grief and despair--I had my hopes up, but the expert had little to say.

What about the psychosocial effects on the siblings of a special health care needs child? We have another daughter at home, who is seventeen months older than Brigette. She could not get the attention she needed; she, too, was carted to doctors' offices and physical therapy sessions often several times per week. If mom and dad are depressed, a sibling will get still less from them. As time passes, this can take quite a toll. Also, parents can look to older siblings, or for that matter, all healthy siblings even if they're several years younger than the handicapped child, to take on a great deal of responsibility. Consider a seven year old child trying to help her three year old sister with cerebral palsey, as she goes into a seizure; or a ten year old child helping his fifteen year old quadraplegic, brain-damaged brother as he aspirates--consider the experience of a sibling with such responsibility, as the child enters a life-threatening situation--and what if the child dies?

This discussion brings to my mind a now middle-aged woman, who illustrates some harmful effects of having been an older sister with too much responsibility for her younger handicapped sister, while she was growing up. Briefly, she had learned to deny her own needs, but could not avoid deep feelings of resentment, lowered feelings of self-worth, was prone to shame, and later found herself living to serve the demands of others, as she was easilly

manipulated by guilt.

Continuing with the effects on siblings of a special needs child, who does the healthy child play with? Driving our healthy daughter to other children's homes was difficult in the early years of our situation, as was driving the kids to the park--so she suffered from the isolation which her mother also suffered from. In our case, our home has come to look like Toys-R-Us, as we kept buying toys for entertainment--this helps, but does not replace socialization experiences.

Now let us consider some psychosocial effects on the child who experiences the disabilities. I remember when I was in the first grade, I chased a six year old girl around the classroom to kiss her on the cheek. She was real cute! In six months she was stricken with spinal meningitis. After that, she was severely impaired. She walked with braces--and all through grade school, junior high, and high school, she struggled through the halls to her classrooms. You could tell that some weeks were harder for her than others. There were the inevitable times when she was inadvertently slammed to the hard floor by a careless child in the halls--I can still hear the clacking of her braces and the heavy sound of her body hitting a hard floor as she fell--and she would be hurt. Kids made fun of her. She did not go to any dances. She struggled to talk clearly. But she always returned a smile. And every night, her father walked her around the block....

Now, our daughter is bright. Her understanding that something is terribly wrong is growing deeper every week. In her case, she does too well to be placed in a school room for severely handicapped kids, so we've "mainstreamed" her into a public co-op nursery program--where she cannot do many of the things everybody else does,

every day. She makes some friends, but cannot keep up with them. For a long time--three years--my wife walked her, every day for hours, my wife on her knees. Finally, Brigette began to walk very precariously, but she could walk. This brought brightness to her eyes--she thought she would soon run and jump like everyone else. It has not happened--she is almost five now--again, she suffers from severe muscle weakness, muscles just have not grown--she is very thin, her back curves markedly--she wears a body brace and ankle braces--and she feels different from the other kids. And there have been the surgeries, and nightmares later of bright lights and strange people in white coats. She is fortunate compared to many--but she is hurt quite often when other kids play around her instead of with her; she is left out; she is beginning to feel inferior, less than everybody else. Just how far will this go? She is realizing she will be limited in many ways--and, I believe she wonders how long she will live. She withdraws, denies, takes "naps" to escape bad feelings, fantasizes being well--and our hearts our broken.

I worry--will she be rejected, knocked down in school? Will she be asked to school dances? I do not think she will be a cheerleader, or march in the marching band. And will she know the great joys of marriage and being a mother herself. All the issues concerning the reactions of parents to the birth of a severely handicapped child can apply to the child too--a growing awareness, at some level, of loss, grief, anger, hopelessness, and despair. And, assuming the child is mentally capable, add to this list a feeling of personal shame, feelings of worthlessness, of being a burden, of being alone in a shallow society that worships material things and physical beauty.

Remember that in a family, everybody effects everybody else.

It's like a living organism--a damaged part can harm the whole, and a healthy part can help the whole. Everybody in the family is important.

So what kinds of services should be provided, and who should provide them? Let us go back to the hospital when Brigette was born. Imagine a team of professionals, trained in mental health skills, being involved. The team might consist of the following: one coordinator to insure there is not duplication of services, and who orchestrates, runs the show; a social worker; a physical therapist assigned to the child; a nurse who will follow the child; a minister, priest, or rabbi to relate to spiritual issues; and, of course, medical people, such as the family's pediatrician, the obstetrician, and perhaps other specialists such as an orthopedic physician, a neurologist, a nutritionist, or other person needed in a given specialized situation. (In our case, our pediatritian coordinated services for us--he did a good job--but physicians do not have enough time to do all that is needed, or to provide continued follow-up services).

Initially, the team functions to help the parents cope with the grief, blaming, guilt, feelings of hopelessness, etc., by providing integrated crisis management--you may wish to consider this as prevention services. Certain members of the team will be involved more than others, as needs dictate, throughout the next several years. The team's involvement would decrease during times of stability and increase during times of crisis, for example, hospitalizations, life cycle issues such as coping with problems in adolescence, and family crises such as marital problems. abuse, alcoholism, etc.. Specific team members might be added or deleted

over time, as needs dictate, but those most involved should remain the same, as often as possible. All team members are trained in basic mental health skills--problem identification, and relationship skills. The team relates to other teams, and all teams receive on-going training and support by a centralized agency whose function is to develop the teams, and a myriad of other services for the target population. Basically, all team members are able to provide a mental health intervention, and together present an initial support system.

Some other important functions of the teams should include the following: (1) the coordinator can retrieve any available information, such as, medical and psychological information concerning the nature of the child's problem and expected outcome--this information would be available through a newly developed, regionally located clearing house, where all available known information is stored and easilly retrieved thanks to our computerized technology. (2) As people at risk of emotional difficulties are identified, brief intensive psychotherapy is arranged and provided. (3) The coordinator is a contact person who the family can call, any time, throughout several years ahead. (4) Based in an on-going team assessment, the coordinator helps the family with educational planning, follows the family as the child enters the educational system, helps in transportation problems, alerts the family to recreational opportunities, arranges for financial planning, helps with insurance problems, helps the family to be aware of programs for which they can apply, and helps the family in filling out the forms.

Another service to be developed is a twenty-four hour telephone "hot line"--so a parent could call a "listening ear", or for information in the case of an emergency. Also, a call could be

made for general education, as the hotline personnel would have access to the general computerized clearing house.

Support groups are also developed, and made known to the parents before they leave the hospital; if possible, an initial contact is made by a support group member. Such support groups could become more important than they currently are. At this time, they are usually organized and maintained by exhausted, overwhelmed, angry, discouraged mothers--so many groups are poorly attended, and flounder. I believe such groups should be developed and maintained by a mental health practitioner--monthly newsletters could be developed for the groups benefit--and babysitting and transportation should be provided--otherwise, they will not reach enough of the target population. I can envision networks of support groups developing in each state, with their own identities and functions.

Intervention teams, clearing houses, hot lines, and support groups can all help facilitate early parent-child bonding, and on-going positive mental health through educational, medical, and emotional support services, and thus help prevent the breakdown of our families. But, they cannot provide intensive brief or long-term psychotherapy. Psychotherapy is expensive. Mental health boards have seen their budgets be slashed--the new rage is to advocate brief psychotherapy, with clear-cut goals and methods. Simple-minded therapies are being lauded, and people are being denied the benefits that only a significant relationship with another person can bring. In my opinion, psychotherapy should be available to all children and their families, whenever they need it. If six sessions are all that are needed, fine--but if fifty sessions are needed, that has to be O.K., too. And it's <u>not</u> up to professionals to alone decide whether or not someone needs therapy. It should be

enough, at least at the outset, that someone in the target population asks for help. And what kind of therapies should be offered--they must encompass the full range of individual, family, marital, and group psychotherapy. And the specific orientation should vary across individual clients and their therapists. Consider for a moment just how complex and varied this target population is--consider all the possible medical conditions involved, the socio-economic and educational backgrounds, etc.--and very important, consider the premorbid personality characteristics of the parents and families involved--e.g., the presence of personality disorders, and all the other diagnostic conditions in the DSM-III-R. We definitely need professionals, who are aware of the complexities involved, and the personality styles and problems presented.

Then again, who should provide direct mental health therapy? In most communities, professionals who could provide some such services already exist. Contracts could be developed, for example, with community mental health board programs, which could, with new financing, provide travelling social workers and psychologists to provide direct services. Also, private practitioners could be hired to work in such a system. Such therapists will have to be willing to travel to the homes of our families, as well as be available in a centralized office setting, perhaps other than their own office. The more cooperation with existing public programs and private practitioners, the better. New positions would therefore be created for CMH boards and private practitioners to fill.

My fantasy runs like this. A major new program is created to serve the psychosocial needs of children with special health care needs and their families; services are to be provided in the homes of those who could not travel to a centralized service

center. For those who could travel, the experience might look like this. Imagine you are taking your special needs child, and, as in my case, her sibling to physical therapy. You drive to a beautiful new complex--as you enter, you pause at the receptionist's desk. She has access to the computerized clearing house of information on a national scale. You ask for an update on new research in the area of your child's problem; perhaps there are new services for which you can apply. You then drop the healthy sibling off at a playroom, where adult supervision is available, and you procede to the physical therapy appointment. There, the therapist gives you instructions for manipulations you can perform at home for your child--you leave her for the remainder of her therapy hour, and procede on to your adult exercise class in the workout room. At the end of the hour, both kids can play in the supervised playroom, while you go to your group psychotherapy session for support and sharing, or to individual psychotherapy to get help with periodic depression. Your child's doctors also come to this center one day a week or so to provide medical services on contract. After your appointments, or in the evening, or on weekends, you can take your whole family to the large, warm swimming pool, also in this building, where other families are playing together. And in very difficult times, you can leave your child, if you need to, in the respite center in a wing of the same building complex, while you get time for yourself. So--all needed services are available in one pleasant, centralized location in your region--no one has to travel to several different locations each week.

I hope I have not sounded too negative in my description of life for the special needs child and their families. I have tried to illustrate the fact that their problems are very real, and that it is very important that they be given attention. Consider

the damage to thousands of people which will otherwise continue to occur, the corresponding waste of human potential, and loss of quality life for so many people. Psychosocial services will make a difference.

I want to close on a positive note. Our four and one-half year old is quite remarkable. When she was still two years old, she said she was "magic". When asked what she meant by this, she said, "I'm 'I can' magic". And, recently she had a dream in which she learned how to stand up from the middle of the floor--the next morning, she tried the "method", and it worked--she stood up, for the first time, without using anything for support. She is determined; she can be a delightful blabber mouth; and we love her. Paraphrasing from an article by Robin Polver, entitled "You Will Grow Because of This", "I love her, and the miracle of that love calms me at the core."